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Parents' views on factors that help or hinder breast milk supply in neonatal care units: systematic review

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ABSTRACT

Objective To synthesise what is known about the parents' views on factors that help or hinder breast milk supply during their infants' hospitalisation in neonatal intensive care units (NICU).

Methods A systematic search of PubMed, ISI WoK, PsycINFO and SciELO, targeting studies presenting original empirical data that examined parents' perspectives regarding breast milk supply experiences in NICU, was performed. Based on content analysis, three independent researchers synthesised the findings of seven studies. Categories of facilitators and barriers were identified using quotations stated in the studies: parents' breast milk supply experience; parents–professionals relationships; characteristics of the NICU; and parents' social background and expectations.

Results The studies, five qualitative and two mixed methods, were published between 1994 and 2011. With heterogeneous study designs, fathers' perspectives were analysed in one article. Only one study defined breastfeeding. According to parents' perspectives, successful breast milk supply in NICU depends on coherent and accurate knowledge about its techniques and benefits, reinforcement of mothers' motivation and alignment between NICU's routines and parents' needs. Parents perceived issues related to their own current breast milk supply experience, simultaneously, as main facilitators and barriers. Parents–professionals relationship constituted the second group of facilitators, but the fourth of barriers. The characteristics of the NICU were more relevant as a barrier than as a facilitator.

Conclusions Although parents' perspectives are grounded on individual child-focused experiences, their emphasis on learning and motivation guided by short-term goals opens room to the collective intervention of experts. This may facilitate the engagement of mothers, fathers and health professionals on family-centred care.

What is already known on this topic

- Parents are key actors for successful breast milk supply in neonatal intensive care units (NICU).
- Very few studies have focused on the psychosocial needs and opinions of parents which have repercussions on infants' health and well-being.

What this study adds

- According to parents' perspectives, successful breast milk supply depends on knowledge, reinforcement of mothers' motivation and alignment between NICU's routines and parents' needs.
- The results highlight the need to invest in qualitative and quantitative research regarding parents' views on breast milk supply during hospitalisation in NICU.
- This approach may improve knowledge and optimise the engagement of mothers, fathers and health professionals on family-centred care in NICU.

INTRODUCTION

The prevalence and duration of breast milk supply among infants admitted to neonatal intensive care units (NICU) tend to be lower than that of full-term infants,[1 2] despite the documented benefits of maternal milk for babies and mothers.[3] Breast milk has been associated with several protective effects regarding multiple medical problems related to prematurity.[4] In fact, feeding human milk to preterm infants may impact their long-term health and development.[5–7] Additionally, the contribution of breast milk for an early and enhanced infant–mother attachment has been previously described.[8] For mothers of infants hospitalised and in an incubator, breast milk may provide a major and unique opportunity to hold and physically connect with their infants.[9]

The perinatal clinical situation has been described as an important predictor of the success of breast milk supply,[10] with the admission to NICU being one of the strongest predictors of not being exclusively breastfed at discharge.[11] The vulnerability of preterm infants and the unique challenges posed by the NICU setting, with the separation of the baby from the mother, difficulties in establishing and maintaining a milk supply and having to deal with health professionals in that sociotechnical environment[2 12] contributed to understand lower rates of breast milk supply among children hospitalised in NICU. In Europe, breastfeeding rates at discharge for very preterm infants varied from 19% in Burgundy (France) to 70% in Lazio (Italy), and were higher in countries with high overall breastfeeding rates.[1]

While parents are key actors for successful breast milk supply in NICU, literature highlights the involvement of health professionals, and the availability of adequate equipment and facilities.[13] Very few studies have focused on the psychosocial needs

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and opinions of parents,[14 15] which have repercussions on infants' health and well-being. In the last decade, other systematic reviews have synthetised mothers' and fathers' experiences and perceptions of breastfeeding support[16] and the barriers to breastfeeding in preterm infants,[2] but they did not access these issues exclusively during the NICU hospitalisation, a setting with specificities that can impact breast milk supply.

Furthermore, listening the parents' voice is a core need for a quality family-centred care,[17] defined as provision of care that is respectful of and responsive to individual parent's preferences, needs and values.[18] Therefore, we aimed to analyse and summarise what is known about the parents' views on factors that help or hinder breast milk supply during their infants' hospitalisation in NICU.

METHODS

The electronic databases, PubMed, ISI Web of Knowledge, PsycINFO and SciELO, were searched to identify all the studies presenting original empirical data on parents' views about facilitators and barriers to breast milk supply during the hospitalisation of babies in NICU. The search covered the full range of publication dates from inception until December 2012, with the expression: "Parents" AND ("perspective*" OR "experience*" OR "Knowledge" OR "Decision Making") AND "Intensive Care Units, Neonatal" AND "Breast Feeding". In PubMed and SciELO, search terms were included as Medical Subject Heading (MeSH) terms. Twelve publications were identified.

The flowchart showing the systematic review process is presented in figure 1. First, studies were excluded based on title and abstract assessment. Three reviewers independently evaluated the studies, following a priori defined criteria for inclusion: written in English, French, Spanish or Portuguese; original studies that evaluate the experiences, knowledge and decision-making regarding breast milk supply during hospitalisation in NICU. Whenever the abstract of a particular article was not available, full text was considered for evaluation.[19] The full texts of the selected articles were then evaluated to decide on their eligibility and availability of relevant data, and five papers were excluded.[19–23] The main reasons for their exclusion are presented in table 1. The bibliographic references of the six publications eligible for inclusion were screened to identify potential articles, one additional paper was included.[24] The three independent reviewers also extracted and synthesised the following data from publications included in this systematic review. First, aiming to characterise the studies, data regarding the year and country of data collection, type of study/methods for data collection, timing of data collection, setting, number of participants, eligibility criteria and breastfeeding definition were collected. Additionally, the first author matched all the keywords mentioned in the studies with MeSH terms and the respective MeSH categories,[25] in order to understand the main medical subheadings addressed in the papers. Second, based on content analysis,[26] categories of facilitators and barriers to breast milk supply in NICU were identified through quotations stated in the studies. These were then summarised in four main categories of facilitators/barriers, according to the protocol for a thematic analysis[27]: parents' breast milk supply experience; parents–professionals relationships; characteristics of the NICU; and parents' social background and expectations. The frequency of each theme and category was recorded. Disagreements in abstractions were discussed and resolved by consensus. An almost perfect strengthen of agreement was achieved.[26]

RESULTS

Study characteristics

The main characteristics of the seven included studies in this systematic review[24 28–33] are presented in table 2. The studies were published between 1994 and 2011, and five were qualitative and two were mixed methods. The most common method for collecting data was the semistructured interview. Studies were conducted in Sweden (n=2), USA (n=2) and England (n=1), and two publications did not provide this information.

The period of data collection ranged from 6 months to 2 years and 5 months, in the three studies that reported it. The timing of data collection was highly variable across the studies, ranging from 1 to 2 weeks after admission to the NICU until 3 months after infant's discharge from hospital. Three out of the seven studies did not report when data collection took place. The setting also varied between the studies, with only two studies including several neonatal units.[28 31]

The number of participants ranged from 9 to 178 mothers, and only one study also examined the fathers' perspectives on facilitators and barriers to breast milk supply in NICU.[30] The eligibility criteria of the participants were heterogeneous but, in general, single mothers, those who were not able to speak the native language and those whose babies had congenital malformations or were very close to death were excluded. The socioeconomic characterisation of the participants was very succinct or absent,[24] which in articulation with the different settings, timing of data collection, eligibility criteria and sample sizes makes it impossible to compare the studies directly. Furthermore, only one article defined breastfeeding, considering it as 'skin-to-skin contact that occurs when an infant's face touches the mother's breast with the intention of having the infant suckle the nipple to obtain human milk'.[32]

The MeSH categories of the keywords included in the studies are presented in table 3. The keywords were mainly concentrated in 4 out of 19 MeSH categories: Persons (n=4), Psychiatry and Psychology (n=4), Phenomena and Processes (n=4), and Health Care (n=3). Only the MeSH terms "Breast Feeding", "Lactation" and "Intensive Care Units, Neonatal" were included in more than one article. Two papers did not present keywords,[28 32] and one-third of keywords did not have a MeSH term attributable.

Facilitators and barriers to breast milk supply in NICU

Parents perceived issues related to their own current breastfeeding experience as mothers and fathers as the main facilitators and the main barriers to breastfeeding in NICU (table 4). In particular, its facilitators were the contribution to infant's growth and well-being, the sense of 'normality', the opportunity to hold and connect with the infant and the learning of techniques to breastfeed, as well as the knowledge about infant's and women's bodies and behaviours. On the contrary, difficulties with pumping and worries surrounding inadequate milk supply emerged as the main barriers.

The relation between parents and health professionals constituted the second group of facilitators, but the last group of barriers. Although the staff perceptions of the parents' and infants' needs may differ from those of parents, mothers and fathers highlighted the importance of positive, consistent and continuous reinforcement and feedback to stimulate mother's motivation and the provision of accurate information regarding breast milk supply strategies and techniques.

The characteristics of the NICU proved a higher relevance as a barrier than as a facilitator. The stressful nature of the NICU,

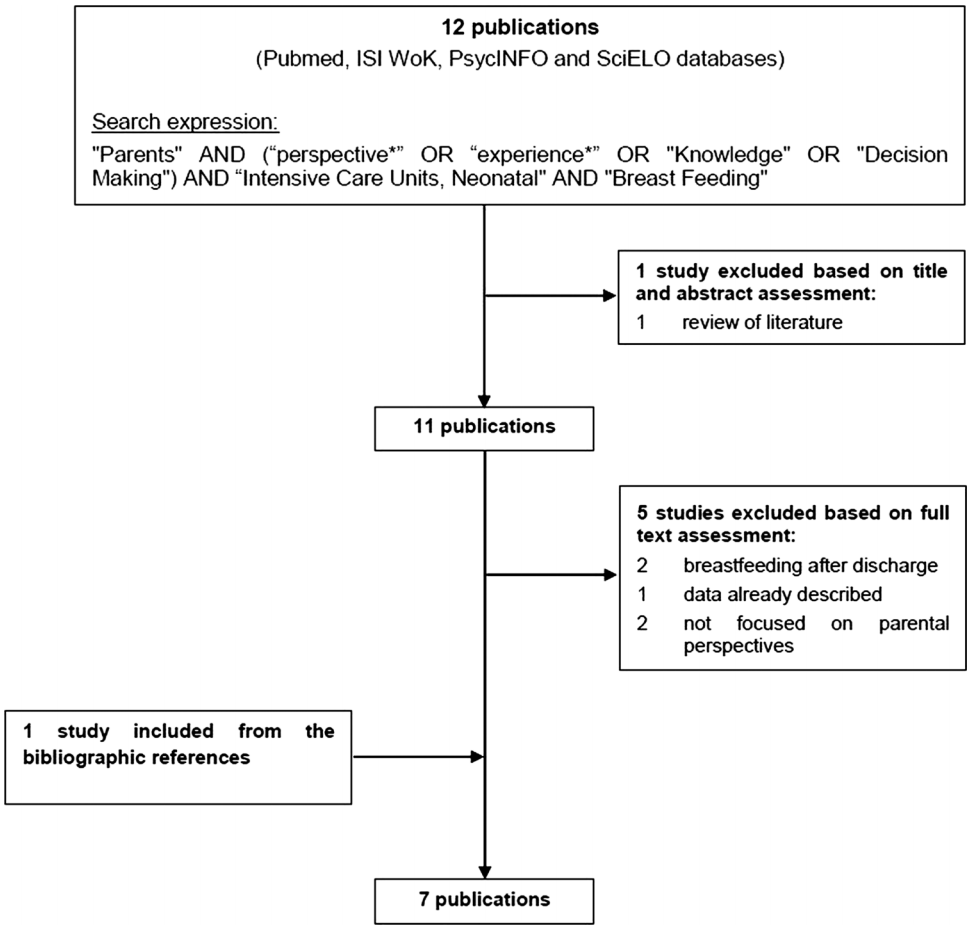

Figure 1 Systematic review flowchart.

the physical separation from infants, the lack of privacy and the structured feeding routine provided a large contribution to the barriers, while the availability of peer counsellors and sterile supplies, as well as the perception of the NICU environment as comfortable facilitated breast milk supply.

Parents' social background and expectations were perceived as neither main contributors nor barriers to a successful breast milk supply experience in the NICU. While it reveals the lowest relevance as contributors, lack of role models and/or social support, isolation and competing time demands were highlighted as barriers.

DISCUSSION

This study assessed the published evidence on parents' perspectives regarding the facilitators and barriers to breast milk supply of children hospitalised in the NICU, according to which a successful experience is linked with three main issues. The first group concerns coherent and accurate knowledge about breast milk supply, namely regarding techniques for expression and storage of breast milk, its benefits and women's and newborn's bodies and behaviours. The second group includes continuous and positive feedback with health professionals to stimulate mothers' motivation. The latter refers to the alignment between the NICU's routines and the parents' needs, while safeguarding the privacy and proximity between mother, father and child. The findings highlight the multifaceted nature of breastfeeding as a gendered embodied experience,[34] in the sense that it is perceived, simultaneously, as a biological and social phenomena or process (with parents emphasising, as main facilitators of breast milk supply in NICU, knowledge of its nutritional and health benefits and physical and emotional closeness with infants) and a female issue (only one of the studies included in this systematic review considered the perspectives of the father).

For mothers with infants hospitalised in NICU, the opportunity of establishing such physical and symbolic connection may be the only context where they are able to hold or care for their infants and feel involved in their growth and well-being, which will interfere with the development of the bonding between mothers and infants.[35] In fact, one major dimension of the infants' care concerns the nutritional aspects, due to the importance of giving adequate milk to the child for optimal weight gain and growth, contributing to the improvement of his/her actual and future global health status.[36] Breastfeeding generates situations that promote the development of women's sense of

Table 1 Main reasons for exclusion of the publications

First author, year of publication	Exclusion criteria
de Souza, 2010[20]	The data described in the paper focused the experiences of breastfeeding after discharge
Dweck, 2008[21]	The study was not focused on parental perspectives
Hallbauer, 2002[22]	The study was not focused on parental perspectives
Miracle, 2004[19]	Data already described in another paper included in the revision[29]
Wataker, 2012[23]	The data described in the paper focused the experiences of breastfeeding after discharge

Table 2 Main characteristics of the studies

First author, year of publication	Period of data collection	Country	Type of study/methods for data collection	Timing of data collection	Setting	Number of participants	Eligibility
Nyqvist, 1994[24]	September 1989–August 1990	Sweden	▶ Qualitative and quantitative ▶ Descriptive ▶ Infants' medical records and telephone interviews	3 months after discharge from the unit	NICU of the University Hospital, Uppsala	178 mothers	▶ Swedish-speaking ▶ Whose infants were full-term singletons (37–42 gestational weeks), had no congenital malformations and were not treated with intensive care techniques (such as oxygen, continuous positive airway pressure, assisted ventilation and/or total parenteral nutrition) ▶ Whose infants were admitted to the NICU within the first day of life and discharged from the NICU within 6 days
Jaeger, 1997[28]	NR	England	▶ Qualitative and quantitative ▶ Cross-sectional ▶ Semistructured questionnaire	NR	Neonatal care units of 3 London hospitals	44 mothers	▶ English-speaking (except if a translator was available) and who were themselves well ▶ Whose babies were not very close to death or when the staff did not consider them inappropriate for inclusion ▶ Whose preterm or sick neonates were admitted to the neonatal care units for more than 6 days and less than 3 months after delivery
Miracle, 2004[29]	NR	USA	▶ Qualitative ▶ Descriptive ▶ Demographic questionnaire and semistructured interview	At least 30 days postbirth	52-bed Special Care Nursery, Rush University Medical Center, tertiary urban NICU	21 mothers	▶ Mothers who stated to intent not to breastfeed at the time of birth, with subsequent initiation of lactation with breast pump and that continued to use the breast pump at 30 days postbirth ▶ Whose infants birth weight was ≤1500 g
Bernaix, 2006[30]	NR	USA	▶ Qualitative ▶ Descriptive ▶ Semistructured interviews	Within 1–2 weeks of the infant's admission to the unit	52-bed, tertiary-care NICU in a free standing paediatric hospital that is part of an academic medical centre	9 mother–father pairs	▶ Mothers married or cohabitating, with at least 15 years of age and that choose to lactate ▶ With a premature infant (between 24 and 32 weeks of gestation), hospitalised in the NICU
Flacking, 2006[31]	January 2001–May 2003	Sweden	▶ Qualitative ▶ Descriptive ▶ In-depth interviews	At least 4 weeks after discharge from the unit	7 NUs spread geographically all over Sweden, 3 at university hospitals and 4 at country hospitals	25 mothers	▶ Swedish-speaking, without life-threatening illness or diagnosed mental illness, who experienced pumping breast milk or breastfeeding during the time in the NU ▶ Whose infants born before 32 gestational weeks and had no congenital malformation preventing breastfeeding or severe illness (such as a cerebral haemorrhage grade III and IV or a chromosome aberration)
Boucher, 2011[32]	NR	Canada	▶ Qualitative ▶ Descriptive ▶ Face-to-face semistructured interviews	NR	Level III NICU in a large urban hospital	10 mothers	▶ Mothers able to understand and speak English or French, whose infants were between 33 and 36 weeks gestational age, that have begun to breastfeed and without a story of substance abuse and/or undergoing methadone treatment ▶ Whose infants had not been apprehended and not had a diagnosis of grade III or IV cerebral abnormalities ▶ Whose infants have been in the NICU for at least 5 days
Rossman, 2011[33]	October 2008–March 2009	USA	▶ Qualitative ▶ Descriptive ▶ Semistructured interview	NR	57-bed tertiary care NICU, Metropolitan Medical Center	21 mothers	▶ Mothers able to speak and understand English, with ≥18 years of age and with at least 3 interactions with a breastfeeding peer counsellor ▶ Whose very low birth weight infant was hospitalised in the NICU and was expected to survive

NICU, neonatal intensive care unit; NR, not referenced; NU, neonatal unit.

Table 3 Medical Subject Heading (MeSH) categories of the keywords included in the studies

MeSH categories	n	MeSH terms	Keywords
Persons	4	Infant, low birth weight Infant, newborn Infant, premature Infant, very low birth weight	Low birth weight infants Newborn Premature infant Very low birth weight infants
Phenomena and processes	4	Breastfeeding (n=2) Lactation (n=2)	Breastfeeding (n=2) Lactation (n=2)
Psychiatry and psychology	4	Breastfeeding (n=2) Breast milk expression Family	Breastfeeding (n=2) Breast pumping Family
Healthcare	3	Intensive care units, neonatal (n=3)	Neonatal intensive care units (n=3)
Anthropology, education, sociology and social phenomena	1	Family	Family
Geographical locations	1	Sweden	Sweden
NA	7	No MeSH term	Breastfeeding decision Breastfeeding support Maternal attainment Mothers' milk Neonatal unit Peer counselling Social bonds

Two papers did not present keywords.[28 32]

herself as a good mother[37] which may contribute for a higher sensitivity during early infancy and secure attachment.[8] Furthermore, breast milk supply may facilitate the establishment of the bonding between fathers and infants, and men's involvement and support have been consistently associated with breastfeeding initiation and maintenance, enhancing family health.[38 39] Therefore, in the context of the NICU, where the development of parental roles appears to be considerably delayed, health professionals must take into account the physical and psychosocial needs of mothers, fathers and infants when offering advice and support to the families in the decision-making process regarding breastfeeding.[37 40]

Our results reveal that parents' perspectives on breast milk supply facilitators and barriers in NICU are grounded on parental personal experiences focused on child hospitalisation. Across the studies, there is almost no reflexivity concerning the influence of parents' socio-economic position and previous expectations around breastfeeding, as well as there are no references to strategies of public health interventions. Although the individual dimension is highlighted in this specific context, parents' emphasis on learning and motivation guided by short-term goals opens room to the collective dimension, where health professionals and expert peers had a vital role in providing coherent information and positive reinforcement, while teaching and training techniques to facilitate rewarding breastfeeding experiences. Furthermore, assisting parents in understanding their infant's signals can allow them to feel more competent in their parental role and, consequently, in their ability to breastfeed.[41] Thus, breast milk supply optimisation stresses the importance of developing health education tools proclaiming its short-term benefits for mothers, fathers and infants, as well as effective communication adjusted to the socio-economic position of each mother and father, giving them the opportunity to ask questions and to voice concerns. In addition, other factors that help breast milk supply than those perceived by parents of children hospitalised in NICU must be emphasised, such as staff training,[13] the engagement of health professionals and the availability of adequate equipment and facilities.

To the best of our knowledge, this is the first study to systematically review parents' perspectives regarding the facilitators and barriers to breast milk supply of children hospitalised in the NICU. Their voices are essential to sustain the design of quality family-centred care,[17] wherein institutional resources and personnel are organised around parents' preferences, needs and values. The adequate incorporation of parents' perspectives into healthcare delivery needs to consider the specificities of the setting. Despite sociocultural specificities regarding breast milk supply and wide differences between NICU, the identification of common facilitators and barriers among countries points the existence of cross-sectional factors that should constitute a privileged target for intervention. A major strength of this study was the use of four search engines supplemented by scanning the reference list of eligible studies, three investigators and two methods of analysis, reassuring triangulation and validation, as well as an almost perfect strength of agreement at intra- and inter-rater reliability.[26]

A considerable heterogeneity was observed across the studies, especially regarding the number of participants, the moment of data collection, the setting and the eligibility criteria. Additionally, the diminutive number of studies included in the review, five qualitative and two mixed methods, performed in very specific settings and, most, with small sample sizes, make impossible the comparison among them. Publications using quantitative methods were not included in our review since those retrieved by the search expression were not focused on parental perspectives regarding breastfeeding in NICU. Furthermore, only one study[32] presented a definition of breastfeeding, which means that each paper could use different definitions not directly comparable. The WHO defines breastfeeding as breast milk being received by the child directly from the maternal breast, expressed or from a wet nurse, not taking into account the physical contact between mothers and infants when classifying breast milk supply as exclusive, predominant and complementary.[42] In accordance with this view, most of interventions to promote breast milk supply in NICU have focused on the physiological benefits of breastfeeding.[2] Even those that value the skin-to-skin contact do it in the sense of improving nourishment, health outcomes and the duration of breast milk supply.[13 43] However, as pointed out in this review, parents often valued breastfeeding as an opportunity to hold and

Table 4 Facilitators and barriers to breast milk supply in neonatal intensive care units (NICU), according to parents' expectations and experiences

	Facilitators Frequency (n)	Barriers Frequency (n)
Breast milk supply current experience	38	27
Nourishment and contribution to infant's growth and well-being	6[28–33]	
Support sense of 'normality'	6[28–33]	
Opportunity to hold and connect with infants	5[24 29–32]	
To learn about infant's and women's bodies and behaviours	5[24 29 31–33]	
To learn about techniques and strategies	5[24 29 31–33]	
Accurate/inaccurate knowledge regarding breast milk supply benefits	4[28 29 32 33]	2[29 30]
Awareness of infant vulnerability	3[28 29 32]	4[24 30–32]
To compensate the baby	3[31–33]	
Use of electric pump versus hand pump	1[28]	
Difficulties with pumping*		7[24 28–33]
Worries surrounding inadequate milk supply		6[24 28–30 32 33]
Delays in starting to express and supplying milk		4[24 28 29 31]
Desire for more rapid weight gain		2[28 32]
Feelings of failure		2[31 32]
Parents–professionals relationships	14	10
Positive reinforcement and feedback (motivation)	6[24 28 29 31–33]	
Provision of accurate information (guidance)	6[24 28 29 31–33]	
Confidence in healthcare providers	2[30 31]	
Staff perceptions of needs differ from those of parents		5[24 28 30–32]
Inconsistent information/conflicting advice		3[24 28 31]
Lack of expert advice		2[24 28]
Characteristics of NICU	11	20
Availability of peer counsellors	4[28 29 31 33]	
Availability/unavailability of sterile supplies	3[28 29 33]	1[28]
Comfortable/stressful NICU environment	3[28 29 31]	5[24 30–33]
Structured feeding routine	1[31]	3[24 31 32]
Physical separation from infants		4[24 28 30 31]
Lack of privacy		3[24 28 31]
Distance (home/hospital; NICU/maternity units)		2[24 30]
'Exclusion' of the father		1[31]
Inability of other family members to visit the infant		1[30]
Parents' social background and expectations	7	13
Parents' mutual commitment to provide breast milk	3[29–31]	
Existence/lack of social support	2[29 31]	3[28–30]
Hope that supplying breast milk will be easier once home	1[32]	
Take the decision before delivery	1[28]	
Competing time demands		3[24 29 30]
Lack of role models		3[28 29 33]
Separation from other family members/friends		3[24 30 31]
Low socio-economic status		1[31]

*Pain, transport of milk, levels of stimulation, feelings of exhaustion and frustration.

connect with infants. Therefore, the message for breast milk supply promotion should articulate the major benefits regarding the nourishment of the child with the opportunity to establish physical contact.

The lack of keywords in two articles, as well as the non-use of MeSH terms in more than one-third of the keywords, may preclude the inclusion of relevant studies, as well as the dissemination of their results to a broad public. Therefore, it is important to stress the need of including keywords in the papers published in the field of biomedical and health sciences and, preferably, MeSH terms, because these are useful tools to standardise the terminology and to clarify concepts and include them into hierarchical categories,[25] contributing to resolve lexical ambiguities.[44]

In conclusion, further research should clearly state the definition of breastfeeding and be performed in different countries and settings, for allowing integration and comparison of findings to better understand parents' perspectives of breast milk supply in NICU. Our results highlight the need to invest in qualitative and quantitative research regarding parents' views on breast milk supply during hospitalisation in NICU in order to improve knowledge and to facilitate the implementation of family-centred care. This may be useful for adjusting psychosocial and educational interventions, and healthcare to each family, mother and father. Such an approach may optimise the engagement of mothers, fathers and health professionals on family-centred care in NICU.

Contributors Each author participated sufficiently in the work to take public responsibility for its content, fulfilling the criteria of authorship. EA collaborated in the acquisition, analysis and interpretation of the data and wrote the article. CR collaborated in the acquisition, analysis and interpretation of the data and reviewed the article. SF analysed and interpreted the data, and reviewed the article critically. HB analysed and interpreted the data, and reviewed the article critically. SS designed the study, collaborated in the acquisition, analysis and interpretation of the data and reviewed the article critically for important intellectual content. All authors approved the final version.

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